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ABSTRACT

This document presents responses of a national telephone survey of 510 parents of children with special needs to find out whether or not parents believe that special education, as it is now structured, is effective. An introduction examines issues related to reauthorization of the Individuals with Disabilities Education Act (IDEA), noting the increased numbers of students identified as disabled, federal funding concerns, and the background of the survey. Major findings report: (1) families recognize that they need special education services but report difficulty getting information on available services; (2) parents report their own children, once in special education programs, have caring teachers and responsive schools; (3) most parents support inclusion of special-needs students in regular classrooms for much of the school day; (4) parents have mixed views on how standards and testing should apply to children with special needs; (5) there exists a vocal and frustrated minority of parents who have serious complaints with their schools and teachers; and (6) many parents object to inclusion of children with behavioral problems in special needs programs and believe that with earlier help many students would not need special education. Details on the survey methodology are attached. (Contains 15 endnotes.) (DB)

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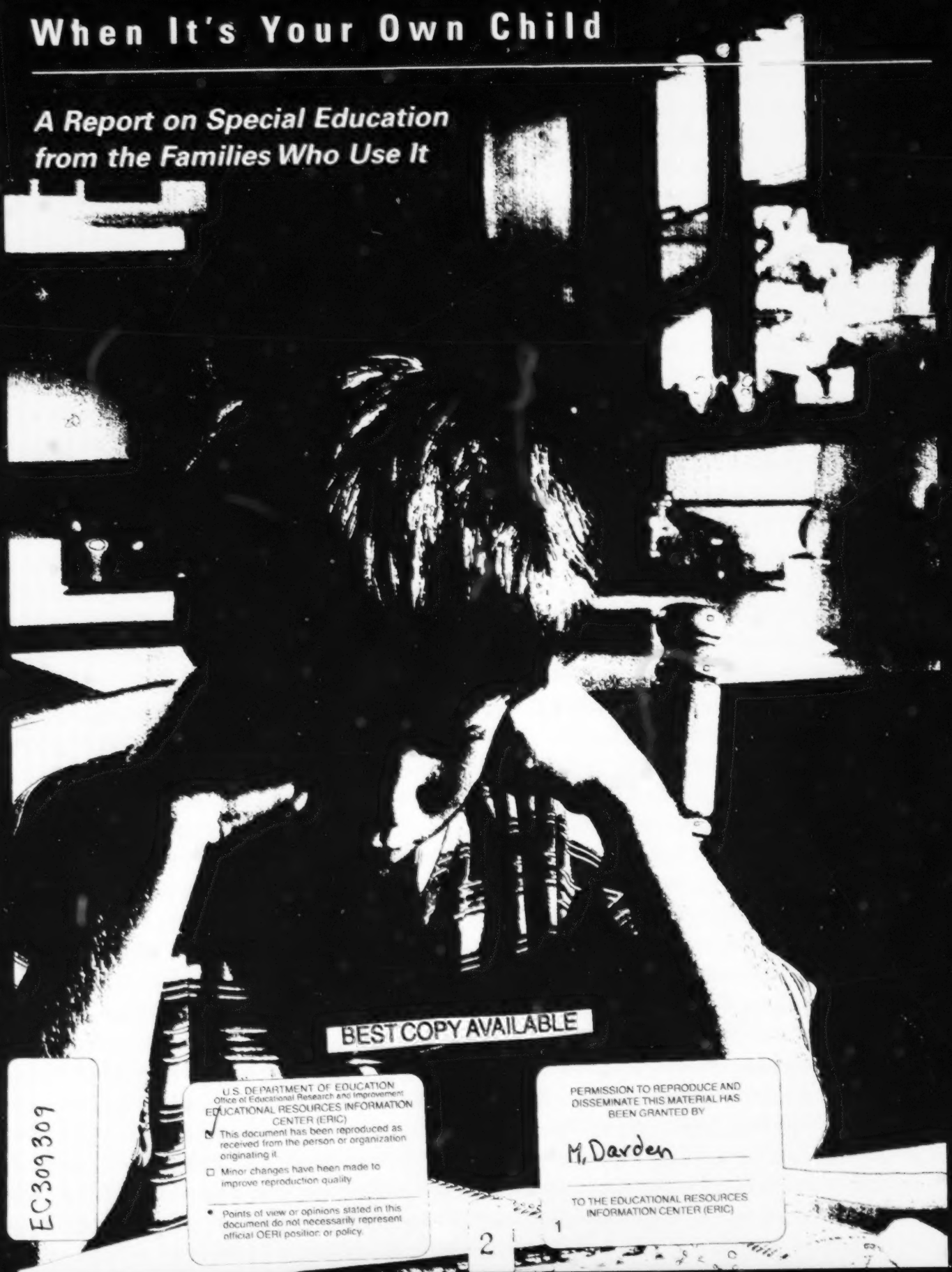
When It's Your Own Child

A Report on Special Education from the Families Who Use It



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When It's Your Own Child

A Report on Special Education from the Families Who Use It

A report from Public Agenda
by Jean Johnson
and Ann Duffett
with
Steve Farkas and
Leslie Wilson

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ABOUT PUBLIC AGENDA

Founded in 1975 by social scientist and author Daniel Yankelovich and former U.S. Secretary of State Cyrus Vance, Public Agenda works to help the nation's leaders better understand the public's point of view and to help average citizens better understand critical policy issues. Our in-depth research on how citizens think about policy forms the basis for extensive citizen education work. Our citizen education materials, used by the National Issues Forums and media outlets across the country, have won praise for their credibility and fairness from elected officials from both political parties and from experts and decision-makers across the political spectrum. Our Web site, Public Agenda Online, provides comprehensive information on a wide range of public opinion and public policy issues.

Over the past 10 years, Public Agenda has examined a wide variety of educational topics including student achievement, academic standards, curriculum, safety and discipline, integration, accountability, school choice, parental involvement, bilingual education and the status of the teaching profession, among others. During this time, we have looked closely at the views of the general public, parents, teachers, students, superintendents, principals, employers and college professors, along with those of key subgroups such as white, African American, Hispanic and foreign-born parents.

6 East 39th Street, New York, NY 10016
Telephone: (212) 686-6610, Fax: (212) 889-3461
Email: info@publicagenda.org
Web site: http://www.publicagenda.org

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Parents of special-needs students voice broad approval of the services they see, but they are receptive to two criticisms. Majorities say that children with behavioral problems—not genuine special needs—are sometimes placed in special education. Most also say that some children in special education would not need these programs if they had gotten help earlier. Still, little from the research suggests any broad call for reform. Most parents know very little about how the programs work or why some might consider special ed in need of reform.

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INTRODUCTION

Few people would argue with the cause. Helping children with physical or learning disabilities is a task virtually all of us expect public schools to accept and act on. Yet, until 1975, when Congress passed the Education for All Handicapped Children Act,* many state public education systems excluded children with emotional or learning problems, along with those who were blind, deaf or physically handicapped.

With the passage of this legislation, Republicans and Democrats, liberals and conservatives, federal, state and local officials, educators and lay people, joined forces to render that statistic a thing of the past. By many measures, their success has been remarkable. Today, approximately 6 million children with physical, emotional or learning disabilities—about 13% of school-aged youngsters—receive special services to help them learn.[1]

"No One Wants to Lock People Away, But . . ."

Yet, over the years the schools' efforts to act on these good intentions have become controversial. In a recent survey of members of the National School Boards Association, almost 9 in 10 (88%) tapped special education as an issue of moderate or significant concern.[2] Problems associated with special education also leapt out in a recent Public Agenda survey of public school superintendents and principals. Challenged by higher academic standards, increased accountability, overcrowded schools, teacher shortages and lagging community support, many school administrators said that special education has become one of the most burdensome parts of their jobs. As one frustrated principal put it: "Our real problem is the time, money and attention devoted to special education at the expense of regular education. No one wants to lock people away and not educate them, but when twenty cents of every dollar is spent on special ed, it is too much."[3]

The 40 Percent Solution

Much of the current controversy is indeed about money. And costs for special education continue to rise, especially when considering the services that are required by many special-needs students. Federal law requires local public schools to provide services for children with special needs, but the U.S. government now provides only about 15% of the money needed to deliver those services. Many want the federal government to commit to providing up to 40% of the funds when Congress reauthorizes special education legislation in its 2001-2002 session, as Congress itself originally promised to do more than 25 years ago.[4]

Does Special Ed Really Work?

But the debate is not only about money. Some critics have suggested that special education has become too bureaucratic, contentious and time consuming for local districts to deal with. Some have begun to ask hard questions about special education itself. Do these programs and services really work? Do they actually help children overcome their difficulties? Why don't more youngsters stop getting special ed services once they start?

Many school administrators said special education has become one of the most burdensome parts of their jobs.

The growth in the number of students identified as "learning disabled" and the increase in the number of children diagnosed with Attention Deficit Disorder (ADD), and Attention Deficit Hyperactivity Disorder (ADHD), also have spawned widespread misgivings.[5] Critics have asked whether some districts or teachers "dump" difficult students into special education because they don't have the skill or the will to help such children themselves. These critics wonder whether better teaching, more consistent discipline and better family counseling might help these children more than special education

* Legislation subsequently retitled Individuals with Disabilities Education Act (IDEA)

does. Many have wondered why it is that African Americans are more likely than white children to be identified as special needs, and why the special education student population is predominantly male.[5]

Are They Being Served?

When It's Your Own Child: A Report on Special Education from the Families Who Use It is an effort to add another dimension to the discussion of these and other questions. It is an in-depth look at the experiences and perceptions of those who are perhaps closest to these issues—the parents of children who receive special education services in the public schools. Through a detailed telephone survey, Public Agenda attempted to learn whether these parents believe that special education, as it is now structured, is effectively serving parents and children. Our intention is to capture their reflections on their experience and include their diagnosis of what special education does well and not-so-well in the national debate.

The Perils of Relying on Lists

When It's Your Own Child is based on a national random sample telephone survey of 510 parents of children with special needs. Conducting the study presented a number of challenges. From the outset, Public Agenda researchers were committed to using a random-sampling technique to identify this relatively small group of parents even though this approach is more expensive and difficult to complete. The easier path is to survey membership groups or collect questionnaires from those who volunteer to complete them. But these techniques—while commonly used—have a tendency to be biased, because they may capture the views of highly active or opinionated respondents, or those who come from particular schools or districts. To our knowledge, *When It's Your Own Child* is the only study to date based on a nationwide, randomly-selected group of parents of special ed children.

Since policies and requirements vary from state to state, defining the term "special needs" also presented some difficulties. For example, there is considerable variation in how a child's status is determined, which disabilities are covered and what kinds of services public schools provide. For this study, a parent of a student with special needs is defined as one who has a child in public school in grades K-12 and who tells us that their child meets one or more of the following criteria: has an Individualized Education Program (IEP); is designated as a Section 504 student; receives special services for ADD or ADHD; or has been identified as a special-needs student or diagnosed with a specific physical, emotional or learning disability. For a full description of the methodology and the sample, see page 31.

Will They Feel Comfortable Talking to Us?

Public Agenda researchers were also initially concerned that parents of special-needs children might be reluctant to discuss their child's situation with strangers over the telephone. We carefully tested and reworked the questionnaire several times to insure that participants felt confident that their privacy would be respected and reassured—that they could be candid. Based on our experience conducting dozens of surveys on many different social, political and economic topics, we were encouraged by the evident comfort level of the parents who agreed to talk with us. In fact, 95% of the parents who participated in the survey said we could call them back again if we had additional questions.

We were encouraged by the comfort level of the parents who agreed to talk with us. In fact, 95% of them said we could call them back again if we had additional questions.

Public Agenda's research on special education was supported by the Annie E. Casey Foundation, the Thomas B. Fordham Foundation and the 21st Century Schools Project at the Progressive Policy Institute. Public Agenda, which takes no position on the debates surrounding special education, was given complete discretion by the funders in conducting the research and reporting the results of this study. Public Agenda takes full responsibility for the research and analysis summarized in this report.

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How Much Do They Understand?

Few readers will be surprised to learn that parents of children with special needs have a different perspective on these issues than many lawmakers, reformers and school administrators. Some of these differences may stem from a lack of familiarity with the larger policy questions now being debated, or from not understanding specifics of the current legislation. These are important, certainly, but they may be easier to iron out than some of the more human dilemmas.

Like most parents, those surveyed here put their own child's interests first. That's human nature and it's what society wants and expects from any good parent. But policymakers have a different charge, and in this instance, it is an enormously difficult one.

An Intricate Balancing Act

Policymakers must weigh all the pertinent questions about special education—how it works, what it costs, how to make it more effective. At the same time, they must weigh the interests of competing constituencies—parents of special-needs children and parents of children who don't need these particular services but who do need good schools and good teachers. With spending for children with special needs averaging over $12,000 per pupil—compared with about $6,500 per pupil for other youngsters—this balancing act is truly an intricate one.[1]

Leaders also have to consider the interests of Americans who do not have children in school, but who need adequate health care, safe neighborhoods, a clean environment and security in an increasingly dangerous world. And they have to listen to the concerns of school leaders and other local leaders who must juggle the funds—and the time and energy—to bring special education services to their local communities.

Like most parents, those surveyed here put their own child's interests first. That's human nature and it's what society wants and expects from any good parent.

A Responsible, Humane Solution

It is often hard to imagine how other people feel and to empathize with their priorities and concerns. But in many ways, absorbing and resolving differing viewpoints is what leadership is all about. As readers will learn in the pages to come, those seeking to improve or reform special education have a difficult road ahead. Our hope is that by providing a detailed rendering of what special education parents experience today, *When It's Your Own Child* will illuminate the national debate and allow us to reach a consensus that is responsible, effective and humane.

FINDING ONE: FAMILIES WHO BELIEVE THEY NEED HELP

Only small numbers of the parents surveyed say schools were in too much of a rush to find a problem with their child. Still, most complain that information about special education is often hard to come by. Most discount the idea that some parents actually push their child into special ed programs, but results are cloudier on whether schools are too quick to label African American children as learning disabled. Parents overall doubt that this is true, but minority parents are divided on the issue.

In the 1970s, when the country first resolved to offer special education in public schools, only about 2% of students were considered learning disabled, and about one child in 12 qualified for some type of special education assistance. By 1999, the number of children assessed as learning disabled had tripled, and about one child out of every eight received special help.[8]

Schools nationwide are grappling with how to pay the costs for special education programs and services, where to find well-trained teachers, and whether to apply new standards and accountability policies to special-needs students and programs. The overarching dilemma is perhaps the most painful one: How should public schools balance the interests of special-needs students with those of the other children they serve? Some critics believe that now is the time to ask whether all children in special education truly need it. Are educators, they wonder, sometimes too quick to label children as "special needs?"

One Powerful Message

When It's Your Own Child is not the definitive answer to this question. After all, this is a study of the perceptions of parents whose children currently receive special education services, and many may be reporting only what educators or other professionals have told them. Still, the research does contain one powerful message for those seeking to reform special education. Whatever the truth may be, the vast majority of the parents we surveyed seem convinced that their own child needs special education, and, in many cases, they say they fought an uphill battle to secure this help.

Whatever the truth may be, the vast majority of parents surveyed seem convinced that their own child needs special education, and often they say they fought an uphill battle to secure this help.

A Long Search for Answers

As we show in later findings, this group of parents does not dismiss all of the observations made by the critics of special ed, nor do they believe that every single child getting special education needs it. Yet their perspective is often the polar opposite of the system's critics—reformers and school officials—who see a rapidly expanding system and who fear that teachers and parents may have become overeager to place children in it. In contrast, parents see services their child needs that are not very easy to get.

Based on results from this survey and from conversations with parents in focus groups, it is evident that many special ed parents simply cannot envision what their children's lives would be like without the special services their school offers. Many have experienced the pain and confusion of watching their child struggle to learn. Often they describe an extended search to get answers. Frequently, they voice gratitude to those who helped them out of their dilemma.

No Recruitment Centers

In this study, only 11% of the parents surveyed say that during the evaluation process for their child, the school seemed to be "in too much of a rush to find a problem." In contrast, 29% say the school was "dragging its feet," while 55% give local schools credit for taking "the right approach."

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Rather than having special education services thrust upon them, many parents complain of precisely the opposite problem. They say that information about how special education works, what it offers and what their child is entitled to is not easy to come by. A large majority (70%), for example, say that too many special-needs kids "lose out" because their families are "in the dark about the services they are entitled to." Well over half (55%) say that parents have to find out on their own what is available—"the school is not going to volunteer the information." Thirty-five percent of parents say that they strongly agree with this statement.

"If You Weren't So Persistent..."

One mother of three special-needs children told us in a focus group: "There is so much out there that the school never tells you about...If you know about it, you can get the service, but they'll never offer it to you." Another mother described her exchange with the school psychologist: "You know what [he] told me? He said 'if you weren't so persistent, I wouldn't give you these services.'"

Some critics have suggested that there is a subset of parents who actually seek to have their child identified as learning disabled or as having special needs so that they will be eligible for special accommodations and services. Most of the parents we surveyed—although certainly not all—reject this notion. Most (55%) discount the idea that some parents push their children into special ed just to get extra resources "even if the children don't really have special needs;" however, 32% say this is sometimes the case.

Since schools generally follow strict privacy guidelines, it is reasonable to ask whether parents can report accurately on the situations that other families face. In focus groups parents often told us they didn't really know a lot about other special-needs students or, in some cases, even who they were. Perhaps more to the point is the reaction of these parents to the suggestion that any family would actually want their child in special education. As one mother of a high-functioning autistic child put it: "No one has ever called me lucky."

Are Schools Rushing to Find Problems?

How would you describe the school's evaluation process?

% of parents who say:	
School took the right approach	55%
— OR —	
School was dragging its feet	29%
— OR —	
School was in too much of a rush to find a problem	11%

Base: Child identified as special needs after age 3 (n=417)

Is Racism at Work?

One particular area of controversy is whether schools and teachers are too quick to label African American or other minority children as learning disabled or having other special needs, and whether this reflects a subconscious or even blatant streak of racism in public education. Here, the insights from the survey are mixed. Overall, special ed parents seem to discount this analysis. Just 18% of the general sample of parents agree, although a very large percentage (41%) admit they don't know. Minority parents, however, are significantly more likely to suspect bias. Among African American and Hispanic parents, 44% say schools are too quick to label African American youngsters as having special needs, although 33% reject this notion and about one in four (24%) also say they don't know.

Public Agenda's1998 study, *Time to Move On: African American and White Parents Set an Agenda for Public Schools*, found that many African American parents fear that their children are more likely to be singled out as learning disabled, although it also raised questions about whether diagnostic testing is actually

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more prevalent for African American children. In *Time To Move On*, the number of African American and white parents reporting that a teacher or school had suggested their child be tested for a learning disability or ADD was similar: 29% of African American parents and 32% of white parents. But among the black parents who said the school had suggested their child be tested, more than one in four (27%) feared their child's race was a factor.*

A Different Mindset

For policymakers and reformers charged with evaluating and perhaps rethinking the nation's approach to special education, the ramifications of the research go far beyond any specific finding. The essential message is not whether these parents agree or disagree with policymakers on any particular point of analysis; it is that parents whose children have special needs come to these questions with an entirely different mindset.

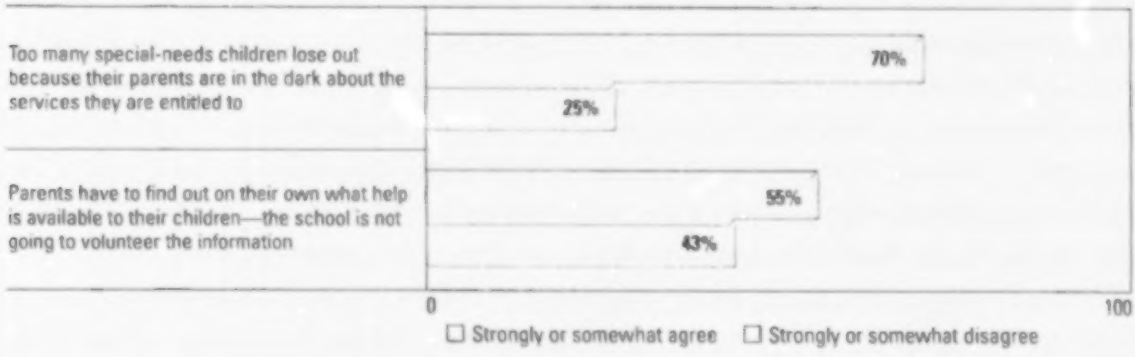
Many did not anticipate that special education would play a central part in their child's school life. Many endured a period of emotional turmoil as they came to accept the fact that their child was having problems in school. One father, for example, talked about his own experience: "It was hard for me to accept that my son had a problem. I wanted to have a perfect kid, my first son. I wanted him to play ball…but no, he can't play basketball because he doesn't know how to follow directions. So the other kids beat him up, push him out of the way…It's hard to see my son suffer like that."

A Deep Sense of Protectiveness and Loyalty

The findings suggest that the parents interviewed for this project feel that, at last, someone has recognized their child's needs, and seemingly all display a deep sense of protectiveness toward their child. Unlike leaders, many parents are not looking at the quality of the education system or public schools overall. They are not looking at school budgets or pondering how public education will fare in the "out-years." They are not struggling with staffing issues or how to balance special education against the many other demands and goals of public schools. As we report in later findings, most seem utterly unaware that there is even a national debate on special education policy. For these parents, as with almost any parent, their first concern, their first priority, their first loyalty, is to their own child.

Information Not Easily Available

How much do you agree or disagree with the following statements?


Too many special-needs children lose out because their parents are in the dark about the services they are entitled to
70%
25%
Parents have to find out on their own what help is available to their children—the school is not going to volunteer the information
55%
43%
0
100
Strongly or somewhat agree
Strongly or somewhat disagree

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FINDING TWO: CARING TEACHERS, RESPONSIVE SCHOOLS

Despite the difficulty of getting good and adequate information about what special education could offer their child, most parents of special-needs students report that once their child is in the program, schools do a good job. Parents say that teachers are caring and knowledgeable, and they give their own school good marks for providing high quality services. Parents are divided on whether special education gets sufficient resources.

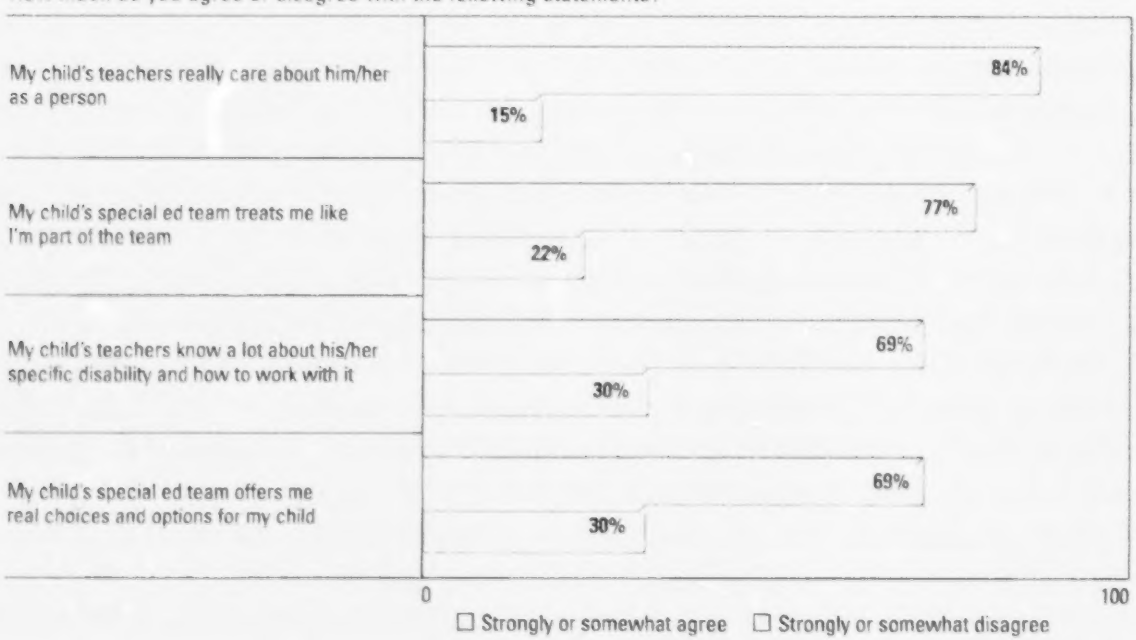
Caring, Knowledgeable

Once their child has been diagnosed and assigned to get special services, most parents of special-needs students give special education a remarkable vote of confidence. More than eight out of 10 parents surveyed (84%) say their child's teachers really care about him or her "as a person," with two-thirds (66%) saying that they strongly agree with this statement. Almost seven in ten (69%) say the teachers "know a lot" about their child's disability, with nearly half (48%) saying that they believe this strongly. Large majorities also give their child's special education team good marks for offering them "real choices and options" for their child (69%) and treating them like they are "part of the team" (77%).

In the survey, we probed parents' views about their child's teachers by specifically mentioning some problems that might arise, but relatively few parents seem to have experienced them. Most (61%) disagree with the proposition that their child might be doing better if he or she had better teachers, and well over a third (36%) say they strongly disagree with this suggestion. Most (60%) also disagree that their child's teachers have trouble managing behavior and discipline

Good Ratings for Special Ed Staff?

How much do you agree or disagree with the following statements?


My child's teachers really care about him/her as a person
84%
15%
My child's special ed team treats me like I'm part of the team
77%
22%
My child's teachers know a lot about his/her specific disability and how to work with it
69%
30%
My child's special ed team offers me real choices and options for my child
69%
30%
0
100
Strongly or somewhat agree
Strongly or somewhat disagree

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in the classroom. And as a final piece of evidence that this group of parents appreciates and respects the teachers they see, 72% give their school a good or excellent rating when it comes to the "skill and quality" of special education teachers. In the focus groups, many parents talked about teachers who had gone the extra mile for their child. "The teacher goes out of her way to work with parents and to learn exactly what their child needs," one mother explained.

Once They Knew...

Schools also receive good reviews. Almost 7 in 10 of the parents (67%) say that their current school is doing a good or excellent job giving their child the help he or she needs. Almost six in 10 (59%) say the school is a good or excellent source of information about learning problems and disabilities.

In focus groups, parents often described the period when their child was first identified as a time of uncertainty and, for some, considerable anguish as the family faced the prospect that their child might have more than the typical growing pains. As we reported earlier, many report that schools are slow to volunteer information about what they could offer.

Still, when it comes to the evaluation process, most parents say schools did their job well. More than 6 in 10 (63%) say it was "clear and straightforward;" just 24% saw it as "complicated and tricky."

More than 6 in 10 parents (64%) also say that once the school knew their child had special needs, getting help was easy (43% say it was very easy). This mother's comment was not unusual: "I finally got my son placed in a school that I'm truly happy with...First of all, [the program] has anywhere from six to eight children and four teachers in the classroom. It's a multi-handicapped class, so it's geared for that. I love the small classes. They take them out into the public, so that they can be with the other people. They treat them like normal people. I just like the way everything is set up."

Although strong majorities of special ed parents give their schools and teachers enviably good marks, this does not mean that accolades are universal. While most African American and Hispanic parents, low-income parents and parents whose children have severe disabilities are satisfied with special ed overall, they are not as satisfied as parents in general. And, as we report in Finding 5, there is a sizable group of parents who are highly dissatisfied and often vocal about their frustration and disappointment.

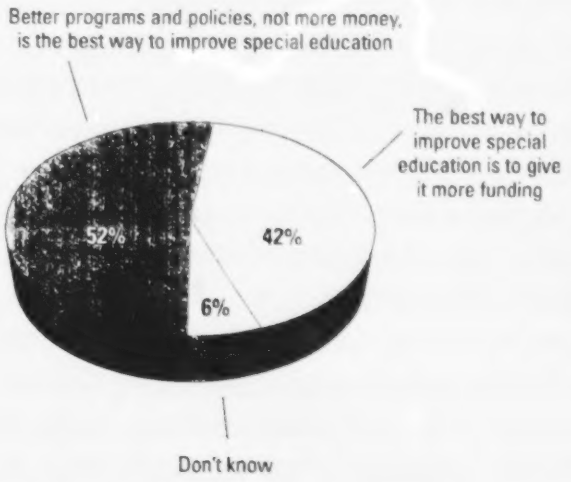
The Unfunded Mandate

For school officials, the question of funding is often the predominant one. In a recent Public Agenda survey, superintendents and principals expressed strong concern about special education as an "unfunded mandate"—one that is required by the federal government but paid for mainly out of local monies. More than 8 in 10 school superintendents (84%) said that they have to use a disproportionate amount of money and resources on special education.[10] Securing federal money to support 40% of the expense—as opposed to the current 15%—is a matter of Congressional debate as lawmakers weigh reauthorization of IDEA.

In focus groups for this project, very few special ed parents were well informed about the funding issues

More Money or Better Programs?

Which of the following comes closer to your own view on how to improve special education?


Better programs and policies, not more money, is the best way to improve special education
The best way to improve special education is to give it more funding
52%
42%
6%
Don't know

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that make headlines in newspapers and education journals. Many of these parents admitted that they know very little about where the money comes from, or how much is needed to pay for the services their child relies on. In this, they are not much different from parents of school children overall. Public Agenda's research over the last decade suggests again and again that parents seldom have the same detailed command of facts and figures as policy analysts.[11]

More Money or Better Programs?

Still, even when considering the question from their perspective—Do the services my school offers generally seem well funded?—parents' views on this crucial issue are mixed. We asked parents to rate local schools on whether they had enough resources for special education. More than half (53%) give their local schools good or excellent ratings, but more than 4 in 10 say their local school is either failing (10%) or needs improvement (34%) in this regard. And amid the generally stunning reviews for special ed professionals, there is one less-than-stellar result: 40% of parents say that they are "too interested in protecting the district or trying to save it money," although 53% say this has not been the case in their experience.

Parents also give mixed signals on perhaps the major issue facing policymakers and reformers today: What is the best way to improve services for children with special needs? More than four in 10 parents (42%) say the best way is to give special education more funding, but more than half (52%) say that "better programs and policies, not more money" is the answer. Given the conventional wisdom that parents always want more money spent on the school services their own child uses, this mixed result qualifies as downright surprising.

Given the conventional wisdom that parents always want more money spent on the school services their own child uses, this mixed result qualifies as downright surprising.

FINDING THREE: SPECIAL EDUCATION TODAY

According to their parents, most special-needs students spend the better part of the school day in regular classrooms, not separated from other students. Regardless of the severity of their child's disability, most parents believe special-needs children are best served by this arrangement —for reasons both academic and social. According to most parents of special-needs children, the social stigma attached to special education is fading, and few feel resentment from other parents for the services their child gets.

In the focus groups and interviews conducted for this study, parents recalled how children with special needs were treated back when they were in school. "Those children were put in basements; they were put in institutions," said one mother. "Our children wouldn't have the opportunity to go to school at all," said another.

But special education programs—and the populations they serve—have changed dramatically since those days. For one thing, the schools' definition of a special-needs child has evolved and now includes not only those with serious physical and/or mental handicaps, but also those with milder learning disabilities. Parents now report that most of their child's school day is spent in regular classrooms. Parents also believe their child experiences far less stigma than he or she would have in the past. Through changes in law, educational philosophy and social attitudes, inclusion—main-streaming or placing a child in the "least restrictive environment"—has become the spirit guiding how districts operate their special education programs.

Today's Profile

This national random sample survey of parents of children with special needs offers an interesting portrait of special education today. Two-thirds (67%) say their special-needs child is a boy and one-third (33%) say it is a girl. Most parents identified their child as either having a learning disability (32%), ADD or ADHD (22%) or a speech or language impairment (13%). Smaller numbers named mental retardation or emotional disturbances (7%), hearing or vision problems (4%), orthopedic impairments (4%) or other serious handicaps (2%).*

Most parents also report their child's disability was discovered at a relatively early age. Nearly one third (31%) of parents say their child was first identified as special needs before kindergarten; another 29% say it happened in kindergarten or first grade. By third grade,

The First to Suggest

Who was the first to suggest that your child should be evaluated by a professional for special needs or learning disabilities?

% of parents who say:	
A teacher	40%
You	33%
Child's doctor	13%
Someone else working for the schools	7%
Another family member	4%
Someone else entirely	3%

* In the survey, parents were asked, "Would you please tell me the category of your child's disability?" Most responses to this question were coded into the categories named above (see Methodology for details). For the purposes of analysis, the categories were further coded into two general groups: relatively "mild" and relatively "severe" disabilities. This distinction is subjective and is not intended as a definitive statement on the seriousness of any particular disability.

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the vast majority (83%) of parents say their special-needs child had been identified as such. Often, it was the parents themselves (33%) who were the first to feel that something was amiss and to suggest their child be evaluated by a professional. In almost half the cases, it was a teacher or other school employee who made the suggestion.

Views on Mainstreaming

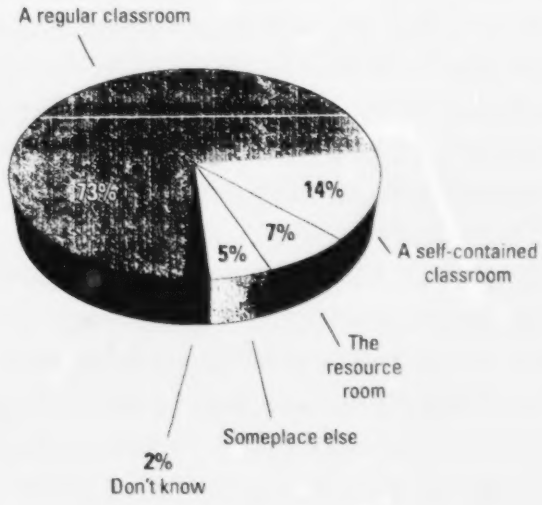
One of the main provisions of IDEA is that students be provided with an education in the "least restrictive environment," which in practice has meant mixing students with special needs and those without in the same classroom. Most parents with special-needs children appear to have accepted this approach, and schools nationwide seem to be acting on this directive.

Almost three in four parents (73%) report that their child spends "most of the school day" in a regular classroom—only 14% are in a "self-contained" class. A slight majority (51%) say their child receives five or fewer hours of special services during a typical school week; one in seven (14%) say their child gets more than 15 hours weekly. Not surprisingly, parents of children with relatively severe disabilities are more likely to say their child is in a self-contained classroom or gets more than 15 hours a week of special services in school.

When it comes to academics, a majority (56%) of parents of special-needs children believes that mainstreaming helps these students learn; 24% say it hurts them and 12% say it has little effect on their learning. The survey also asked special-needs parents whether they think mainstreaming special-needs children interferes with the ability of "other students" to learn. A plurality (44%) feels that mainstreaming has little effect on students without disabilities, 27% believe that it helps them, and a relatively low one-in-five (21%) feel that mainstreaming hurts the other students. There are virtually no differences between the parents of severely disabled and mildly disabled children on the effects of mainstreaming.

The School Day

Where does your child spend most of the school day?



"Inclusion and It's Good"

For many policymakers and educators working on the issue of special education, the driving focus is academic learning. But for parents of special-needs students, the social aspects are often just as important—learning how to get along with others, making friends, playing schoolyard games. In this area, mainstreaming plays an especially important role. "In the beginning he was in [special classes] all day, from the moment he got off the bus until he came home to me," said a mother of a 19-year-old son with developmentally-delayed autism. "I didn't like that because I didn't feel like he was being given the social skills…Now he goes to high school [and] he goes to each and every one of those rooms… it's the contact with normal people. First of all, for them to see you. Second of all, for you to see them and learn how to interact." A mother of a younger child also commented, "If we only had a playgroup all the time

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with just kids with Asperger's, how are they going to learn appropriate social skills? They're not going to learn it from each other. They need typical models. That was the idea for inclusion and it's good."

"A World of Difference"

Of course some parents do believe their special-needs child is better off spending most of the school day with children who are at their level, rather than in a mixed classroom. A mother of a sixth-grader with Down's Syndrome described how her daughter's life improved when she moved from spending most of her day in a regular classroom to a self-contained one: "Last year…she totally hated school, didn't want to go… This year they decided to have a self-contained class. It has made a world of difference. She's in a class of four kids who are on the same reading level as her…she's happy as a little pea in a pod."

"I Think They Feel Sorry for You"

Some news accounts suggest that parents of non-disabled kids are resentful of special education and up in arms that their own children—who make up the overwhelming majority of the school population—get shortchanged as a result. But Public Agenda's findings suggest that if this kind of uprising is indeed happening, the large majority of special ed parents simply aren't picking up on it. Eighty-five percent report they have never felt resentment about special education from parents of other students. "I don't think they resent our kids' services, ever," said one parent. "I think they feel sorry for you."

Almost 7 in 10 parents of special-needs children (69%) agree that "there's much less stigma attached to being in special education than there used to be," and 37% strongly agree with this statement. A mother of a child with a severe hearing disorder commented about her daughter's school experience: "There is absolutely nobody who ever, ever makes her feel any different than anybody else. Teachers here, they never, ever make her feel any different…Never once has she felt out of place." Another parent explained: "There are so many kids nowadays that are pulled from the classrooms to go to reading resource or to speech. So the term 'stupid' or 'your child is not as bright as the others' is kind of going away. It's not 100 percent gone, but it doesn't feel so bad because there's other kids that leave too."

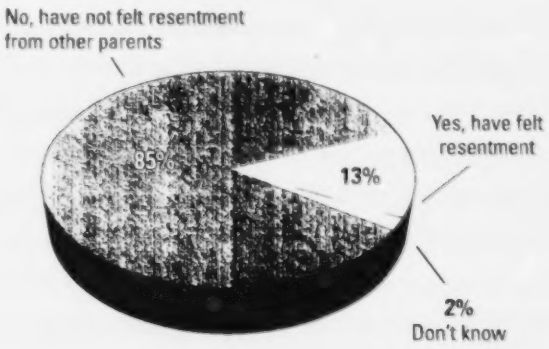
Judging from our interviews, it may be the children who are "borderline" who remain most vulnerable to teasing. They may look normal but get teased by other kids because of quirky behavior or because of clumsy social interactions. In a focus group, a parent of a high-functioning autistic child said to a mother of a mentally retarded child, "I don't want to say this, but it's our children who would be more teased, I believe, than yours…." The mother agreed, "They would never tease a child with Down's Syndrome."

Kinder, More Considerate?

There is evidence that this is all part and parcel of an evolving cultural shift in society regarding the way people with disabilities are treated. Earlier this year, Public Agenda surveyed 2,013 Americans nationwide and asked them to rate how good a job the public is doing when it comes to being kind and considerate toward people with physical handicaps. Sixty-one percent said people are doing an excellent or good job, and more than half said things have gotten better compared to the way things used to be.[12]

Little Resentment from Other Parents

Have you felt resentment toward special education from parents whose kids don't have special needs, or is this something that you have not felt from other parents?



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FINDING FOUR: MIXED VIEWS ON ACADEMICS AND STANDARDS

On the whole, parents of special-needs children are optimistic that their child can make academic progress, and their overall views on standards and testing are very similar to those of other parents. Still, they have mixed views on how these policies should apply to youngsters with special needs. Most say these youngsters should have some accommodations made for a high school exit exam or be allowed to take an easier test.

Opinion polls over the last several years have shown broad support for putting more emphasis on academic standards in public schools. President Bush's No Child Left Behind Act makes annual testing in math and reading the law of the land for third through eighth graders—with stiff penalties for schools that fail to raise student achievement. Yet as school systems nationwide act to put higher standards in place—to strengthen promotion and graduation standards—questions emerge about how these new policies should apply to youngsters with special needs.

Needing a Leg Up?

As we will see in the next few pages, the parents of special-needs children want schools to put more emphasis on academics in their child's education. *Reality Check*, Public Agenda's in-depth annual survey on standards and testing, suggests that their overall views are very similar to those of parents whose children do not have special needs.[1] At the same time, a number of findings suggest that academics are not the foremost issue for most special ed parents. Many believe that special-needs children may need a leg up to reach their goals, and as we have seen, making progress in the realm of social interactions can be just as important to parents—if not more so—than academics.

The vast majority of special ed parents (79%) agree that the schools should be paying a lot more attention to the academic progress of students in special education, with nearly 6 in 10 (59%) saying that they strongly agree with this sentiment. And special ed parents—like parents in general—reject the concept of social promotion, that is, passing children along to the next grade whether or not they have learned the required material. In *Reality Check*, parents of children with special needs said—by a 67% to 28% margin— that it is worse for a child who is struggling academically to be passed to the next grade and expected to keep up than to be held back and have to repeat the year.

Social Promotion in Action

In focus groups, some parents told surprisingly explicit stories about their firsthand encounters with social promotion. One father described his conversation with a teacher when his daughter was promoted from eighth to ninth grade: "How in the world does my kid pass [when] she got three Fs?," he asked the teacher. 'Well, Mr. X, we don't want to make them feel like they can't be with the other kids. We don't want to get them down. We want to keep trying. That's why we move them on.'" Another mother complained: "...My son had four D's, and they were more than willing to send him to the next level without giving him any extra help. That's failing the kid. [Then] they said he couldn't go to summer school because he didn't have an 'F.'"

Parents of children with special needs said—by a 67% to 28% margin—that it is worse for a child who is struggling academically to be passed to the next grade and expected to keep up than to be held back and have to repeat the year.

But as genuine as these feelings are, it is also clear from the survey that raising academic standards is not the top priority for most special ed parents. Asked to choose among four issues (other than money) facing special education in their own school, just 8% pick raising academic expectations as the biggest issue. More than a third (35%) say the focus should be on helping students sooner; 29% would put the emphasis on cutting bureaucracy and red tape, while 23% say the main problem is a need for better teachers.

The juxtaposition of these two findings—the vast majority of special ed parents who say that academics should get more emphasis versus the small number who see this as a top priority for their own child's school—suggests something of the tension and ambivalence that many of these parents feel. Most special ed parents would probably recoil at the idea that schools or teachers would just give up on teaching academic subjects to their children. Like other parents, they accept the notion that higher expectations help children put in their best effort. At the same time, most wouldn't want their children humiliated or devastated by impossible demands, and they believe that some accommodations should be made. "We need to level the playing field. That's how you look at it," explained one parent.

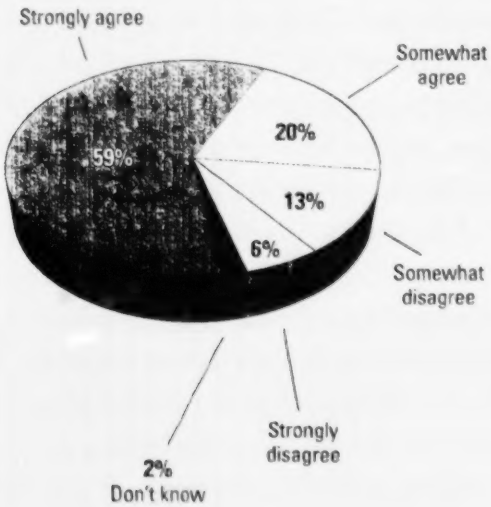
Looking Forward to a Cap and Gown

On the whole, parents are optimistic that their child can make academic progress. For example, 60% of the parents surveyed describe their child's academic abilities as average or above; 38% say they are below average. Among parents overall, more than 4 in 10 (43%) anticipate a time when their child will no longer need special help, compared to roughly a quarter (27%) who think their child will always need special education, and another 29% who say the future is uncertain. As might be expected, parents of severely disabled children are much more likely to say their child will always need to get some special education (53% vs. 18% of parents of children with mild disabilities). Nearly all of the parents whose children are in high school (82%) say they expect their child to receive a standard diploma.

In focus groups, parents were often dismayed by the idea of labeling special-needs children as perpetual underachievers or writing them off in terms of academic achievement. One father spoke from the heart when he said, "What I don't want to have happen is [for] my son to get out of high school and get a degree and not know what he's supposed to know."

Academics Important, but a Lower Priority?

Do you agree or disagree with the following statement? The schools should be paying a lot more attention to the academic progress of special-needs students



Other than money, which of the following four issues do you think is the biggest issue facing special education in your school?

% of parents who say:	
Students need to be helped sooner	35%
— OR —	
There is too much bureaucracy and red tape	29%
— OR —	
Better teachers are needed	23%
— OR —	
Academic expectations should be higher	8%

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Should Special-Needs Students Take Exit Exams?

If your state required high school students to pass an exit exam covering basic skills and knowledge to get a high school diploma, would you want your child to:

% of parents who say:	
Be required to pass the same test	34%
— OR —	
Pass the same test but with special accommodations	50%
— OR —	
Be excused from the test	4%
— OR —	
Take a different, easier test	11%

"I've Got to Learn to Do It Myself Someday"

Sometimes parents talked about the courage and resolve of their children, or their own commitment to having their children do their best even when it is difficult. A mother whose son is dyslexic described his decision to take the S.A.T. exam. "That's going to be difficult for him. But he's of the mind that 'I've got to learn to do it myself someday.' He doesn't use it as a crutch. He never has." She also talked about her child's difficulties with a recent statewide test: "He did not pass it the first two times. And it took sitting down and talking to him, 'Read them [the questions] and try answering the best way you can.' And he did it and he passed...He's not excused from anything."

Yet as optimistic and determined as these parents are, many have mixed feelings about exposing their children to the same testing and accountability requirements that other youngsters face. Most do believe that tests can be a useful motivator. Almost 6 in 10 (58%) of the parents surveyed say that if special-needs students were required to take the same standardized tests that regular education students take, both the students and their teachers would take academics more seriously.

The Same Test or an Easier One?

Still, most also believe that some flexibility is needed for special-needs children to thrive. Two out of three (66%) say they worry about pushing students to take tests if they cannot possibly pass them, with 38% saying that this comes very close to the way they feel. In this survey, we asked parents directly: If your state required high school students to pass an exit exam covering basic skills, what kind of test would you want your child to take? More than a third (34%) say their child should take the same test as other students under the same circumstances, but half (50%) say they would want their child to take the same test but with special accommodations. About one in ten (11%) say they would want their child to take an easier test, and 4% that they would want them to be excused from the test.

"He Would Never Get Out"

In focus groups, parents described their concerns. "Everybody isn't on the same level," one father said, "and some kids should be exempt from that proficiency test because they will never pass." A mother talked frankly about the prospects for her own child, now a second grader: "My concern is this dumb proficiency test that they've got these kids taking...Once he gets to fourth grade, then what's going to happen? He would never get out. He'd be 21 in fourth grade trying to pass that proficiency test."

"Once he gets to fourth grade, then what's going to happen? He'd be 21 in fourth grade trying to pass that proficiency test."

—mother of a 2nd grader

In some districts, controversies have already emerged over whether special-needs students should take statewide standardized tests and whether their scores should be included when the results are evaluated.[14] Some critics of special education believe that school officials sometimes excuse special-needs students from testing

to keep test scores high for their district. We asked the parents surveyed here whether they think this has happened in their own district, and more than half (53%) say that they don't believe so. Still, a substantial minority (29%) do agree that this may be the case. As a father of a high schooler commented: "There's a lot of pressure on the school system to do well on standardized tests" and for teachers to "teach them how to take the test so that they score well, because it makes the district look good."

"Not a Single Friend"

With all the emphasis on raising academic standards, it is important to note that special-needs parents often view progress on the social level as equally—or sometimes even more—important as academics. But according to many of the parents we spoke to, schools tend to focus on academics at the expense of social development. One father, whose 9-year-old autistic daughter wins chess tournaments, described her challenges in school: "She's advanced in some things, but socially she's kind of a mess. She's got not a single friend." One mother talked about her decision to have her daughter repeat the fourth grade, mostly because she wasn't socially ready to move ahead. She said that the school district doesn't "see it like outside people see it. The way they diagnose within the school district is how it's affecting them academically, what their symptoms are and how it affects what they're learning, not how it affects socially and everything else. Not the big picture."

With all the emphasis on raising academic standards, it is important to note that special-needs parents often view progress on the social level as equally—or sometimes even more—important as academics.

The gap between what schools see as progress and what parents value occurs in other instances as well. And for some parents of special-needs children, important victories may not be apparent to someone else. One mother described her son's improvement in the last year: "Wow. We have come a long way…Transitions were always a hard part for him, and he's getting more flexible. [At] the beginning of last year, he had to have a sheet in front of him [saying] what was going to happen that day… He doesn't need that anymore."

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FINDING FIVE: A VOCAL AND FRUSTRATED MINORITY

While a healthy majority of parents of special-needs children say local schools are responsive and offer high quality services to their child, a substantial number do have serious complaints. Many say they have to fight to get services even after a disability has been identified. Many give their schools and teachers low marks and are convinced that their child would be making more progress if the teachers and programs were better. In the end, one in six special education parents say they have considered a lawsuit.

On the whole, parents report that local schools are responsive to their special-needs populations. But there is a significant minority of parents across the country who are more than a little dissatisfied—and more than a little outspoken—when it comes to what they expect from the public schools.

The Problems Just Don't Stop

As we noted in Finding 1, very few parents say that schools promote special education unnecessarily or seem in a hurry to diagnose children as having a problem that requires special services. In fact, majorities criticize schools for keeping information about special education services close to the vest. However, once their child is identified and begins to receive services, most parents say they are quite satisfied. They give their schools and teachers high ratings for trying hard to help their child.

Yet for large numbers of parents, getting a diagnosis and finding a program does not solve their problems. In fact, it seems to be just the beginning. More than a third of special ed parents (35%) say that it was "frustrating" to get services even after "the school knew your child had special needs," with nearly 1 in 5 (18%) saying that it was very frustrating. More than 4 in 10 (43%) say that they "have to stay on top of the school and fight to get the services" their child needs (compared to 55% who say they can trust the school).

"I'm Frustrated"

In focus groups, dissatisfied parents often painted a picture of special education as an impenetrable, circuitous bureaucracy where no one seemed to have an answer. One father of a 16-year-old voiced his irritation: "[Doesn't anyone] know everything they are supposed to know. Can't [anybody] see from point A to point B to get the right information the first time. I'm frustrated." Another parent told us she is "fighting with the school system all the time trying to make sure they provide the services [my son] needs in order for him to move along as he should." One mother who had her child tested independently of the school district at her own expense said, "It was a very arduous process...

The Less Satisfied Constituency

% of parents who say:	
Their child's special education program is failing or needs improvement when it comes to preparing them for life in the real world after high school*	45%
Their child's special education program is failing or needs improvement when it comes to being a good source of information about learning problems and disabilities	39%
It was frustrating to get the special education services their child needed	35%
Their child's current school is doing a fair or poor job when it comes to giving their child the help they need	33%

*Base: High school parents (n=143)

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I had to go to the school and lay it on the table and say, 'Here's your diagnosis. You are by law obligated to help this child.' It took me six months of back and forth with the school, but they finally did it."

Obstacles and Impediments

Results from the survey confirm this sense that, for some parents, special education is filled with obstacles and impediments. One in three parents (33%) say that the people dealing with special education in their school are too concerned with process and paperwork. Almost four in 10 say their school needs improvement (31%) or is failing (8%) when it comes to "being a good source of information about learning problems and disabilities."

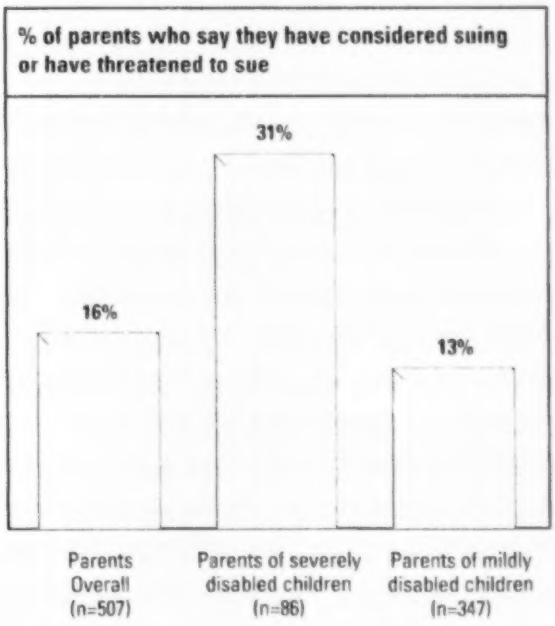
But for these dissatisfied parents, the complaints go beyond the bureaucratic runaround. Many of their criticisms go straight to the heart of the matter—many simply don't believe that the professionals dealing with their child are doing a good job. While a majority of special ed parents do give local schools good or excellent ratings for giving their child the services he or she needs, a not-small 33% say their school is doing a fair or poor job in this area. Similarly, nearly a quarter (24%) give their child's special education teachers low marks on "skill and quality," and a substantial 38% say that their child could be doing better in school if he or she had better teachers.

More than 4 in 10 of the high school parents surveyed (45%) also say that their child's special education program is failing or needs improvement when it comes to preparing them for life in the real world after high school. The parents of high schoolers in the focus groups were especially concerned about this issue. "There's no existing transition program for students leaving high school," said one mother. "It's desperately needed… A lot of these students, they're not going to go on to college…How are you going to take the academic high school experience and now transfer that into the real world…Are you setting these kids up for failure?"

Dissatisfied parents often painted a picture of special education as an impenetrable, circuitous bureaucracy where no one seemed to have an answer.

Who's Most Likely to Sue?

Have you ever considered suing, or threatened to sue, a school district because of an issue related to your child's special needs or IEP, or has this never happened?


% of parents who say they have considered suing or have threatened to sue
16%
31%
13%
Parents Overall (n=507)
Parents of severely disabled children (n=86)
Parents of mildly disabled children (n=347)

Who Considers Suing

Given these grievances it may not be surprising that one in six parents of special-needs children (16%) say they have considered legal action over their child's special education program. And, perhaps contrary to conventional wisdom, it is the parents of children who have relatively severe disabilities (31%) who are more likely to say they have "considered suing or threatened to sue a school district because of an issue related to [their] child's special needs or IEP." For these parents, it may well be that the obstacles they encounter in the schools, combined with their fears for and loyalty to their child, produce an intolerable situation—one that they believe can only be resolved in court.

In the focus groups, more than a few parents talked about the personal sacrifices they and their families

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have made to devote more time to their special-needs child. Many had quit their jobs, giving up a much-needed second paycheck. Others had relocated to a school district with a better reputation for serving special-needs children. Some talked about the incredible expenses they incurred to have their child evaluated by the best, and about the countless hours spent learning how to deal with their child's disability.

"22 Kids in Their Class"

Their concerns notwithstanding, it would be a mistake to conclude that substantial numbers of special ed parents view schools as the enemy, or that they have no sympathy for the difficulties schools and teachers sometimes face. Parents often took pains to point out that teachers and other school professionals have their child's best interests at heart but are sometimes simply spread too thin. "They've got 22 kids in their class, and they can't know everything on the first day. So you have to speak up for your kid and let them know what your child needs," explained one mother.

Walking a Thin Line

Many of these dissatisfied parents are also aware that they have to walk a thin line, lest they antagonize school personnel whose help they ultimately need and who—at the end of the day—are the ones who will teach their child. In one focus group, a more seasoned parent offered words of advice to the newcomers. "When you're an advocate for your child, it's very important not to be antagonistic," warned a father of a high school freshman. "Because then it becomes what they're legally obligated to do for you versus what they're willing to do for you. And what you want them to do is work with you, regardless of what the law is."

"It's very important not to be antagonistic ...Because then it becomes what they're legally obligated to do for you versus what they're willing to do for you."

–father of a high school freshman

FINDING SIX: DO SPECIAL EDUCATION'S CRITICS HAVE A POINT?

Parents of special-needs students voice broad approval of the services they see, but they are receptive to two criticisms. Majorities say that children with behavioral problems—not genuine special needs—are sometimes placed in special education. Most also say that some children in special education would not need these programs if they had gotten help earlier. Still, little from the research suggests any broad call for reform. Most parents know very little about how the programs work or why some might consider special ed in need of reform.

For some in leadership, increasing federal funds for the services that special education provides is the first order of business. Vermont Senator Jim Jeffords, a passionate advocate of increasing U.S. dollars for this purpose, believes that Congress has "woefully failed to meet its obligation to fully fund IDEA."[1] Like others in government and education, he believes that special education is fundamentally sound as currently practiced. From his perspective, the chief task is to insure that *all* the children who might benefit from special ed are able to do so.

Other leaders embrace special education's goals and acknowledge that it has helped millions of children over the last three decades, but they also raise questions. They ask whether some youngsters are placed in special education—not because they have special needs—but because they are not as cooperative or well behaved as classroom teachers might like. Are some youngsters, they ask, tagged as learning disabled because schools failed to teach them reading and other basic skills at the outset? Has special education become too bureaucratic, too bogged down in paperwork, too litigious? Do the services that schools offer really work? Do they actually help youngsters overcome their difficulties and learn as much as they are able to?

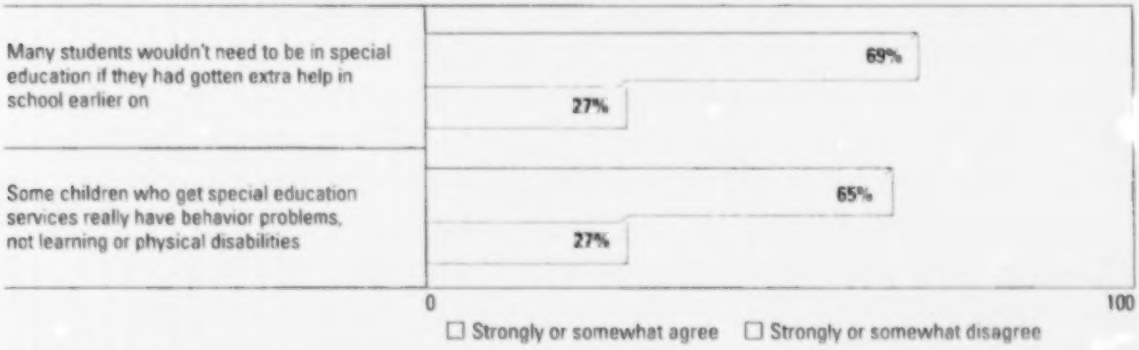
A Different Starting Point

There is no question that most of the parents interviewed for this study come to these questions from a very different starting point. They are not researchers or empiricists or skeptics; they are beneficiaries and supporters. These are people who needed help for their child and got it through special ed services.

Nonetheless, the parents we surveyed do not dismiss all of these concerns out of hand. Almost two-thirds (65%) agree that some youngsters in special education "really have behavior problems, not learning or physical

Do All Children Need to Be There?

How much do you agree or disagree with the following statements?


Many students wouldn't need to be in special education if they had gotten extra help in school earlier on
69%
27%
Some children who get special education services really have behavior problems, not learning or physical disabilities
65%
27%
0
100
Strongly or somewhat agree
Strongly or somewhat disagree

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disabilities," with a third (33%) saying they strongly agree with this statement. Almost seven in 10 (69%) also say that many students "wouldn't need to be in special education if they had gotten extra help in school earlier on," with nearly half (46%) saying that they strongly agree.

Poor Teaching or Special Needs?

Reformers often differentiate between learning problems that stem from poor teaching versus those that stem from a child's own cognitive difficulties, and some critics are persuaded that more effective teaching earlier on (especially reading skills) could dramatically reduce the number of children who need special education. While it is not clear from this research that parents recognize the precise distinctions these reformers make, the findings do suggest they are open to this line of thinking.

Yet beyond this, there is no broad indictment of special education as dramatically off-track. Most of the parents in this study seem comfortable with the diagnosis and services offered to their own child. What's more, healthy majorities give the schools and professionals they deal with quite good ratings indeed.

"I've Never Given Money a Thought Actually"

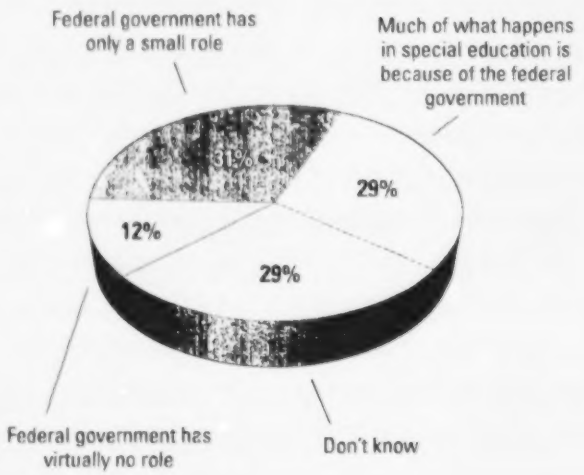
In focus groups, parents often spoke with remarkable clarity about the details of their child's diagnosis and the special education options offered in their district. Yet, not a single parent referred to any of the special ed policy debates now taking place among lawmakers in Washington or among educational decision-makers nationwide. Few were aware of special education's growing costs or any particular controversy about them. When a mother of a high-school-aged boy who gets special services said, "I've never given money a thought actually," another mother in the focus group immediately chimed in, "I haven't either." And, indeed, most of the parents we surveyed readily acknowledge that they do not know very much about how special education works as an educational policy. Sixty-three percent say they are not too familiar with the federal Individuals with Disabilities Education Act that underpins special education nationwide. Just 10% say they are very familiar with it. In a result that may prompt amazement among the nation's public school administrators, 29% admit that they don't know how much of a role the federal government plays in special education, while another four in 10 say that the federal government has either no role at all (12%) or only a small one (31%). Just 29% say that "much of what happens in special education takes place because of the federal government."

Seems Fine to Me

The take-away lesson here is that many of the complexities and tensions that lawmakers, reformers and educators wrestle with seem quite hidden from parents of children with special needs. Superintendents and principals voice broad concern about a disproportionate share of resources going into special education, but the vast majority of parents surveyed here say they have not felt any resentment about this from other parents. Administrators may face a daunting

Are the Feds Involved?

As far as you know, does much of what happens in special education take place because of the federal government, does the federal government have only a small role, or does it have virtually no role in special education?


Federal government has only a small role
Much of what happens in special education is because of the federal government
31%
29%
12%
29%
Federal government has virtually no role
Don't know

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task finding certified teachers for special education, but parents give special ed teachers marks that other professional groups might envy. And while education journals and newsletters may be filled with stories detailing the administrative and legal intricacies of meeting the special education mandate, parents apparently witness very little of this administrative pain. Asked whether the people dealing with special education in their school seem overly concerned "with paperwork and following proper procedures," 63% of the parents we spoke with say this is not really a problem as far as they can tell.

Many of the complexities and tensions that lawmakers, reformers and educators wrestle with seem quite hidden from parents. School leaders voice concern about disproportionate resources going into special education, but the vast majority of parents say they have not felt resentment about this from other parents.

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ENDNOTES

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11. See for example: *Reality Check 1999.* Public Agenda. National random sample telephone interviews of 708 parents of public school students in grades K–12. Asked if they knew each of the following about their child's school, majorities of parents said no: number of violent incidents that have occurred on school grounds (64%); percentage of students from their child's school going on to college (68%); dropout rate (74%); attendance rate at their child's school (77%). See also: Farkas, Steve, Jean Johnson, et al. *On Thin Ice: How Advocates and Opponents Could Misread the Public's Views on Vouchers and Charter Schools.* Public Agenda, 1999. National random sample telephone interviews of 1,200 adults including 394 parents of children in school grades K-12; mail survey of 833 community-based political, civic and business leaders. Page 34.

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METHODOLOGY

When It's Your Own Child: A Report on Special Education from the Families Who Use It is based on a national random sample telephone survey of 510 parents of K-12 public school children who have special needs (margin of error: plus or minus four percentage points). The survey was preceded by three focus groups and four in-depth individual interviews with parents of special-needs students, and 13 in-depth interviews with experts in the field.

The Survey

Telephone interviews were conducted with a national random sample of 510 parents of special-needs students in public school grades K-12. The fielding of the survey took place between April 12 and May 11, 2002. The survey took approximately 20 minutes to complete. The margin of error is plus or minus four percentage points; it is higher when comparing percentages across subgroups.

Respondents were drawn from a random sample of households using a standard, random-digit-dialing technology whereby every household in the region covered had an equal chance of being contacted, including those with unlisted numbers. Out of the 510 interviews, 42 were completed using pre-screened sample from a previous national random sample survey of parents conducted by Public Agenda in 2001. A comparison of the 42 interviews from the pre-screened sample with the remaining 468 interviews shows no substantive differences.

Given the personal and private nature of the survey questions, special efforts were undertaken to make the interview as comfortable as possible for parents. First, the survey instrument was extensively pre-tested with parents of special-needs children before the survey began. Also, interviewers were instructed to do the following, as necessary: inform parents about Public Agenda's reputation as a highly-regarded, nonprofit and nonpartisan research organization; provide Public Agenda's Web site address; and offer to send written information about Public Agenda.

Defining the Sample

To be included in the sample, parents had to meet the following criteria:

1. Respond "yes" to: Do you have a child who has an Individualized Education Program, also known as an IEP, or not? (76% of total sample)

   — OR —

2. Respond "yes" to: Do you have a child who is classified as a "504" student, or not? (7% of total sample)

   — OR —

3. Respond "yes" to the following *two* questions:
   a) Has your child been identified as having ADD or ADHD, or not? *and*
   b) Does your child get special services or accommodations in school to help with ADD or ADHD, or don't you know? (8% of total sample)

   — OR —

4. Respond "yes" to: Do you have a child who has been identified as a special-needs student, or diagnosed with a specific physical, emotional or learning disability? (9% of total sample)

The above is a decision hierarchy of criteria for inclusion in the sample, not a demographic description of respondents' characteristics. For example, fully 90% of respondents actually say their child "has been identified as a special-needs student, or diagnosed with a specific physical, emotional or learning disability," but only 9% of respondents are included in the sample based *solely* on this response. For a comprehensive demographic description of the sample, see the table entitled "Characteristics of the Sample" on page 33.

Subgroup Analysis: Mild vs. Severe

Two analytic categories were created by the researchers—parents of children with relatively "mild" disabilities and parents of children with relatively "severe" disabilities. This distinction is subjective and is not intended as a definitive statement on the seriousness of any particular disability. The categories were based on parents' responses to the question: "There are many different categories of disabilities that a special-needs child may have. Would you please tell me the name or category of your child's disability?" "Mild" includes those parents who identified their child's disability as ADD/ADHD only, as a learning disability or as a speech/language impairment. "Severe" includes those who named mental retardation or emotional disturbance, orthopedic problems, hearing/vision impairments or other severe disabilities. Parents who identified their child as "autistic" are not included in either of these analytic categories because the autism spectrum is so broad and because parents did not elaborate as to the severity in their child. Similarly, a small number of responses in the "other" category were somewhat ambiguous and are also not included in either analytic category.

The Questionnaire

The questionnaire was designed by Public Agenda, and Public Agenda takes responsibility for all interpretation and analysis of the data in this report. As in all surveys, question order effects and other non-sampling sources of error can sometimes affect results. Steps were taken to minimize these, including extensively pre-testing the survey instrument and randomizing the order in which some questions and responses were presented.

The survey was fielded by Robinson and Muenster Associates, Inc., of Sioux Falls, South Dakota. Sample was provided by Survey Sampling, Inc.

The Focus Groups and Expert Interviews

Focus groups allow for an in-depth, qualitative exploration of the dynamics underlying the public's attitudes toward complex issues. For this study, insights from the focus groups were important to the survey design, and quotes were drawn from them to give voice to attitudes captured statistically through the survey interviews. In total, three focus groups were conducted, one each in Connecticut, Ohio and Texas. These groups consisted of parents whose child 1) has special needs and 2) receives special education support and services in public school. Given the difficult nature of recruiting these parents, a trusted local community member was identified in each area to assist in finding parents who met Public Agenda's specifications. All focus groups were moderated by Public Agenda senior staff.

The focus groups were augmented by 13 in-depth telephone interviews with experts in the field, including academics, teachers, administrators, lawyers and leaders of special education associations, as well as by four in-depth individual interviews with parents of special-needs children.

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Characteristics of the Sample

Sex of Parent	%
Male	32
Female	68

Race	
White	77
Black/African American	11
Hispanic	7
Asian	1
Native American	3

Education	
Less Than High School	13
High School Graduate	28
Some College/2 Year Degree	36
4 Year Degree	15
Graduate Degree	9

Income	
Under $25,000	26
$25,000 to less than $50,000	30
$50,000 to less than $75,000	22
$75,000 or more	19

Sex of Child	
Male	67
Female	33

Grade of Child	
K-5	47
6th-8th	24
9th-12th	29

Parents' Description of Child's Disability	%
Learning Disability	32
ADD/ADHD only	22
Speech/Language Impairments	13
Mental Retardation/Emotional Disturbance	7
Hearing/Vision Impairments	4
Orthopedic Impairments	4
Autism	3
Other	8

Grade Child First Identified as Special Needs	
Before Kindergarten	31
Kindergarten	13
First	16
Second	11
Third	12
4th-8th	15
9th-12th	1

Region	
Northeast	20
Midwest	25
South	33
West	23

Urbanicity	
Urban	22
Suburban	50
Rural	28

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